DOCUMENT RESUME

ED 385 076 EC 304 109

AUTHOR	Collins, Edward C.
TITLE	Educational Rights for Students with TS: Your Child's Rights to a Free Appropriate Education. Educational Recommendations.
INSTITUTION	Tourette Syndrome Association, Inc., Bayside, NY.
PUB DATE	94
NOTE	31p.
AVAILABLE FROM	Tourette Syndrome Association, Inc., 42-40 Bell Blvd., Bayside, NY 11361-2874 ($3).
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Attention Deficit Disorders; Compliance (Legal); Due Process; Educational Legislation; Educational Testing; Elementary Secondary Education; Individualized Education Programs; *Legal Responsibility; Mainstreaming; *Neurological Impairments; *Parent Rights; *Parent School Relationship; Student Behavior; Student Evaluation; *Student Needs; *Student Rights
IDENTIFIERS	Individuals with Disabilities Education Act; *Tourette Syndrome

ABSTRACT

This handbook for parents of children with Tourette Syndrome (TS) includes information on the child's rights under the law and legal steps to achieve those rights. Relevant federal laws are reviewed including Individuals with Disabilities Education Act requirements for impartial due process hearings, least restrictive environments, and allowance for assistive technology and transition services. Necessary preparations for a due process hearing are identified, along with tips and reminders regarding the individualized education program (IEP). Recommendations that parents might make to the school are identified concerning: classroom structure and planning; cognitive and visual motor difficulties that the child may exhibit; testing considerations; and problems associated with attention deficit hyperactivity disorder, including impulse control, listening and speaking, written math skills, behavior management, and obsessive compulsive symptoms. Included are a glossary, explanations of the roles of professionals who may work with the child, four agencies to contact for information, and brief annotations for four videotapes and five publications on TS. (SW)

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EDUCATIONAL RIGHTS FOR STUDENTS WITH TS

Your Child's Rights to a Free Appropriate Education

Educational Recommendations

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Introduction

This handbook is written for you as parents. It is to help you with the process of assuring an appropriate educational program for your child with Tourette Syndrome (TS). It covers information about your child's rights under the law, and the legal steps to follow to achieve those rights. There are *federal laws* protecting the rights of children with disabilities. The following is an overview of some important federal legislation. However, the emphasis of this handbook is largely on the requirements of Public Law 94-142, (P.L. 94-142), the Education for All Handicapped Children Act. Amended in 1990, this law is known today as IDEA, the Individuals with Disabilities Education Act (P.L. 101-476).

All your questions and concerns may not be addressed, but hopefully you will find this information of benefit to your child and family. Individuals and families coping with a disability such as TS, a less commonly recognized disorder, might have to be more vigilant in exercising their rights than those with more familiar types of disabilities. You may find many service providers know little about TS. So, as your child's advocate, it will be up to you to provide information about TS to these professionals.

Working with Teachers and School Personnel

Typically, teachers and school personnel are individuals whose primary interest is in children. Often they are hampered by funding limitations and school policies. At times, you may find that educators seem unable to help, or they respond with an educational plan you believe to be less than adequate for an appropriate education. Try not to get discouraged, and be persistent. Achieving your child's rights is not always simple. There may be times when you need assistance or even legal advice. Remember too, educating teachers and staff is not a one-time effort at the beginning of each school year. This process is ongoing and changes each year as children mature, develop and assume more responsibility for themselves. Each school year is another beginning, with new teachers, classmates, and sometimes even a new school. For the welfare of your child, you will need support. Remember to pace yourself, to be realistic, and expect some successes, some compromises, and some temporary setbacks.

When approaching your school system, provide educators with basic information about TS which is readily available from the national Tourette Syndrome Association (TSA) and its affiliates. A broad range of up to date, informative articles, booklets and videos are available.

As parents we want our children to achieve, make good grades, and to do well. However, the decision about what actually constitutes an appropriate education is based on a child's educational needs. The law does not guarantee that any child, disabled or otherwise, will be given help to the extent that he will reach his maximum potential. For example, my child may need to use an index card to keep his place when reading because of constant head jerks. Using a card, my child can read as fast as other children of similar ability. Therefore, he is now being provided an appropriate education. However, whether he does well on a test is a reflection of intelligence level, knowledge and such additional factors as motivation and time spent studying.

TS: Disability, Handicap, or Both?

Tourette Syndrome is a disorder that is not so much "disabling" as it is "handicapping." Strictly speaking, a "disability" refers to a reduced physical or mental ability to do a given task. Disabilities are a "given," and they are absolute. A person does not really have a say about whether he/she has a disability. On the other hand, a "handicap" is a judgment (either by oneself or by others) about whether an individual is hampered by either a physical or mental limitation. For instance, the child with TS may be slow copying from the chalkboard, or his handwriting may look "sloppy" (disability ???), but the slowness or sloppiness is caused by the neurological involvement of TS. It's beyond the child's control, a result of the child's physical makeup, something that he cannot control. However, this particular child also works extra hard at recopying assignments on a typewriter or word processor, and spends extra time after class getting "copywork" completed. Therefore, the disability is not *handicapping* this particular child's ability to function as a student.

For someone with a disability, the seemingly harsh reality is that sometimes this person must do the "extra" to succeed and to avoid becoming handicapped. TS fits the definition of a disorder that is not so much disabling as it is handicapping. This is due in large measure to the attitudes of society toward its unusual symptoms. The child with TS faces attitudinal barriers every day of his life.

Remember, many educators use the terms "disability" and "handicap" synonymously, and often they do not make this important distinction.

National Legislation — A Summary

The following federal laws represent important legislation protecting the rights of children with disabilities such as TS. Following are major highlights from each law.[1] The numbers sighted refer to identified sections from the Code of Federal Regulations (CFR) which is available from most libraries.[2]

Rehabilitation Act of 1973 — This law[3] (Section 504) extends civil rights to children with disabilities. It requires schools to provide an appropriate education to any child with a disability. Section 504 prohibits organizations that receive federal funds (e.g. schools) from discriminating against otherwise qualified individuals solely on the basis of their disabilities. A child who is not eligible under IDEA may be eligible for services under Section 504. Furthermore, Section 504 defines a free appropriate public education, (FAPE), as one "designed to meet the individual educational needs of persons with disabilities as adequately as the needs of non-handicapped persons are met." FAPE is based on adherence to evaluation, placement, and procedural safeguards, similar to, but not the same as those of IDEA. A student must be evaluated to determine if the disability "substantially limits one or more major activities," such as walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself or performing manual tasks. If eligible, reasonable accommodations must be made for the student and a written plan developed for placement and services. However, an IEP is not required. This law also has served as a basis for discrimination cases brought by individuals with disabilities – particularly in their right to employment.

1. "Assistance to States for the Education of Children with Disabilities." Title 34 Code of Federal Regulations, Part 300. 1993 Edition.

2. Each state can add to the provisions of any federal law. Always check your state's guidelines for any additions to and/or interpretations of federal law.

3. "Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving Federal Financial Assistance." Title 34 Code of Federal Regulations, Part 104. 1993 Edition. (This is the source for regulations from Section 504 of the Rehabilitation Act of 1973.)

Public Law 94-142[4] — Passed in 1975, this law concerns the fundamental rights and procedures necessary to ensure that all children with disabilities receive a free, appropriate public education to which they are entitled.

P.L. 94-142 requires that students with disabilities be educated in the "least restrictive environment" (LRE). It also sets out requirements for protection of parents' rights, diagnosis, nondiscriminatory assessment, and for the individualized educational program (IEP) for each child covered by this law.

Handicapped Children's Protection Act (P.L. 99-372) Often referred to as the "Attorney's Fee Act," this 1986 law provides authority for partial or total reimbursement of attorneys' fees after parents go to court to obtain appropriate educational services for their child but only when the decision has been awarded in their favor.

Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) — This law extends the provisions of P.L. 94-142 to include 3-5 year-olds. It also provides incentives for states to develop early intervention programs for infants with known disabilities as well as those considered to be at risk.

Technology Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407) — This legislation is the first attempt to develop a "consumer-responsive, statewide, comprehensive program for the selection and delivery of assistive technology devices and services." The Act makes available competitive grant funds to states for the development of a coordinated system of technological services. It contains a broad set of purposes, functions and activities, which collectively, are intended to increase the ability of individuals with disabilities to secure assistive technology devices and services covered by this Act.

The Americans with Disabilities Act (P.L. 101-336) This 1990 law extends civil rights protection to individuals with disabilities in specific types of private sector employment, all public services, public accom-

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4. Formerly: Education for All Handicapped Children Act

modation, transportation and telecommunications. The law states that public accommodations, businesses, and services such as hotels, restaurants, grocery stores, and parks, cannot deny services to individuals with disabilities.

Individual with Disabilities Act (P.L. 101-476) P.L. 94-142 was amended in 1990. The amendment (P.L. 101-476) changed the title of the special education law to "Individuals with Disabilities Education Act" (IDEA). Currently, IDEA is the most comprehensive federal legislation requiring that children with disabilities such as TS be provided a free and appropriate education.

Specific Rights Under IDEA (P.L. 101-476)[5]

Several major P.L. 101-476 provisions affecting children with TS include:

- Rights of the child and parents/guardians in assessment, identification and placement procedures.
- Nondiscriminatory testing and confidentiality of students' records.
- Rights of parents to an impartial due process procedure, at no cost, when they disagree with the school's decision about their child.
- Development of an individualized education program (IEP) for each child with a disability who is found eligible for services under the law. This includes annual goals and specific objectives based on the child's level of functioning.
- Right of the child to be educated in the least restrictive environment (LRE), and whenever possible, with nondisabled peers.

Parents Rights (34 CFR 300.345, 300.500-300.506, 300.562) — Many parents do not consider their child with TS as being handicapped. Others may perceive their child as severely "victimized" by the disorder. Parents may fear that once their child is "labeled" disabled and receives special treatment or educa-

5. Formerly P.L. 94-142

tional intervention, this labeling might hinder the child in the future. Please know that by law, school records are strictly confidential, and can be released to outside sources *only with your written permission.*

IDEA details the role of parents in the education of their children. Parents have the right to:

- Be notified in writing before the school takes any action that may alter the child's program including testing, identification and change in placement. Federal law, however, does not require parental permission for the three-year reevaluation of a child.
- Grant or withhold permission to have their child tested for eligibility for special education services, or be placed in a different classroom or program. Parental permission can be revoked at anytime.
- Inspect and review all education records with respect to the identification, evaluation, placement and provision of a FAPE for their child.
- Request an independent education evaluation at public expense if parents believe the school's evaluation is inappropriate.
- Participate on the IEP committee that considers the evaluation, placement and educational programming for the child.
- Request a copy of the child's educational record.
- Request a due process hearing concerning the school's proposal or its refusal to initiate or change the identification, evaluation or placement of the child.

Individualized Education Program (IEP) (34 CFR 300.340-300.350) — P.L. 101-476 requires that an IEP be developed and maintained for every eligible student with a disability. Ideally, the IEP is a process for spelling out where he or she is going, how to get there, how long it will take, and how to determine when goals have been met.

IEP formats vary widely across states and school districts. States and individual schools may go beyond the requirements of the federal law and may include

additional information and requirements. Each child's IEP must be reviewed and, as necessary, revised at least once each year. The child's parent or guardian must consent to the IEP and must receive a copy of the document.

The law is specific about what an IEP must include, and exactly who takes part in its formulation. Each IEP must be the product of the joint efforts of a multidisciplinary committee, to include at least: 1- the child's teacher(s), 2- a representative of the local school district other than the child's teacher, 3- the child's parents or guardian, and 4- when appropriate, the child. Other professionals, such as a physical education teacher, speech-language pathologist, occupational therapist and physical therapist may also be involved in the IEP committee meeting.

An IEP must include:

- A statement of the child's present levels of educational performance, annual goals, including short-term instructional objectives.
- A statement of the specific special education and related services needed by the child without regard to their availability, and the extent to which the child is able to participate in regular educational programs.
- The projected dates for both the beginning and anticipated duration of the services.
- The objective criteria and evaluation procedures and schedules to be used for determining (on at least an annual basis) whether the stated instructional objectives are being achieved.
- A statement of the transition services needed for students to begin by age 16, and to be updated annually thereafter. When deemed appropriate for an individual, this statement may be issued at age 14 or younger. It must include a statement of the interagency responsibilities or linkages (or both) *before* the student leaves the school setting.
- A list of the individuals who are responsible for implementing the IEP.

Impartial Due Process Hearing* (34 CFR 300.506-300.515) — IDEA embodies the concept of due process for students with disabilities and their parents. Several key elements of due process as it relates to special education are the parents' right to:

- Have a hearing before an impartial party (not an employee of the school district) to resolve disagreements with the school system concerning the child's educational program.
- Receive a written decision following any hearing.
- A hearing conducted by the State Educational Agency (SEA) or the public agency directly responsible for the child's education. This procedure must be "spelled out" by state statute.
- Be notified of free or low-cost legal and other relevant services such as mediation (available in some states).

Least Restrictive Environment (LRE) (34 CFR 300.550-300.556) — The term "least restrictive environment" means the setting that most closely parallels a regular, standard school program, yet at the same time, one that meets the child's special educational needs. Conversely, the most restrictive environment is a setting that least resembles a regular classroom. For example, a child who is educated at home or in a hospital, would have little or no opportunity to interact with children that attend regular classrooms. Least restrictive environment is a relative concept; that is, an LRE for one child might be inappropriate for another.

Most school districts provide a range of different placement and service options to meet students' needs. Typically, placements range from least restrictive (regular classroom placement) to most restrictive (special schools or institutions). Most children with disabilities are served in regular classrooms, with their individual program modifications (listed in their IEP) being implemented in that setting. The number of children who require more restrictive placements is smaller.

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* See page 11 on how to prepare for a due process hearing.

Assistive Technology (34 CFR 300.308) — Each public agency must ensure that both assistive technology devices and/or assistance technology services are made available to a child with a disability when such services are required as part of special education, related services, or supplementary aids and services.

Related Services (34 CFR 300.16) — The term "related" means transportation and such developmental, corrective, and other support services that are required to assist the child in special education. Federal law lists a range of services such as speech pathology, occupational therapy and counseling services. The list is not exhaustive but may include other services that help a child in receiving special education.

Transition Services (34 CFR 300.18) — Transition services are specific activities designed to promote transition or movement from school to post-school activities. They may include post secondary and vocational training and education. Other examples are outlined in this section of the law. Also, transition services are a requirement for students 16 years of age (and at a younger age, if deemed appropriate). See IEP section for additional information.

IEP Tips and Reminders for Parents

- You must receive a written explanation of your procedural rights any time the school requests your consent, initiates a change, or refuses to initiate a change in the identification, evaluation, placement or provision of a free appropriate public education.
- Actively participate in planning your child's educational program. *Attend all IEP committee meetings.* If you receive notice of your child's IEP meeting and it is to be held at an inconvenient time, contact the school and ask that it be rescheduled.
- Your personal knowledge about your child is important information. Share observations with the IEP committee about your child's behavior, likes and dislikes, situations and environments where your child seems to work best. Inform the committee of any recent changes in your child's life, and future plans for your child.

- Good record-keeping is helpful. Keep copies of all correspondence between you and the school regarding your child's eligibility for special education and his IEP. Keep copies of the scores of all tests given to your child and the results of evaluations. Keep copies of your child's IEPs. This comprehensive record will help establish your objectivity and credibility in working cooperatively with schools. *This point cannot be emphasized enough!*

Due Process Hearing Preparation

In preparing for a hearing, there is much to do for parents, their advocates and their attorney (if they have one). Several suggestions are:

- Review the procedures for due process hearings in your state (available from your State Department of Education).
- Determine which issues you and the school division can agree upon.
- Define the issue(s) upon which you and the school division cannot agree.
- Review the child's records.
- Obtain materials or documents in support of your position to present as exhibits at the hearing.
- Label each exhibit (e.g., student exhibit #1, student exhibit #2).
- Make three copies of each exhibit: one for the parents, one for the school, one for the hearing officer.
- Send exhibit copies to the school and the hearing officer at least **five administrative days before the hearing.** The school division must do the same.
- Decide who should testify for the parents. The witnesses should be individuals who know about the child and can support the parents' position.
- Review the school's exhibits and list of witnesses.
- Decide what questions to ask those witnesses and write them down.
- Decide if the hearing is to be open to the public.

***Note**: Once a due process hearing is formally requested, specific timelines are set into effect. Both you and the school system must abide by this schedule.*

Educational Recommendations*

This section covers recommendations you might suggest to the school when developing a program for your child. Views on how to serve students with disabilities such as TS range from full inclusion, (the philosophy that all students with disabilities should be educated in the regular classroom) to the view that a broad range of services should be offered, e.g. regular classes, special classes, resource rooms, residential settings, etc.

Students with Tourette Syndrome have different problems in varying degrees of severity. However, there is a likelihood that one, some, or all of these potential obstacles to learning may be present: visual-motor impairment, a learning disability, Attention Deficit Hyperactivity Disorder or obsessive/compulsive ritualistic types of behaviors. Advance planning for these possibilities is recommended to avoid later problems with behavior that are costly to the student, the teacher and the rest of the class.

Classroom Structure and Planning

- If symptoms become severe, allow the student a break. When a student continuously diverts energy and attention from learning to inhibiting tics, academic performance suffers. On occasions when a student needs to leave the class because of the built-up tension caused by tic suppression, a discreet signal can be worked out between the student and teacher. A classmate can tape record material that has been missed. (Be careful not to send the student out too often.)
- When vocal tics are present, quiet time or study hall can be extremely stressful environments.
- Allow the child to monitor his own need for leaving the classroom. Tell the student to start taking responsibility for removing himself from situations where his behavior might get him into trouble or increase his anxiety and thus his tics. This is called a "voluntary time-out." Be supportive and share with

* Edward C. Collins, Ph.D. and Ramona Fisher-Collins, M.Ed. Reprinted by permission.

him that you realize this will not be easy, but if he doesn't take responsibility for his actions he will be subject to the same rules and consequences as everyone else in the class. This removes the teacher from making a "judgment" call as to whether the unwanted behavior is caused by TS symptoms or whether it is purposeful.

- Allow for ample classroom space to move about freely.
- Set, communicate, and post behavioral/academic expectations and consequences. Use of behavior modification techniques: response-cost, positive reinforcement, contracting, explicit rules and consequences helps with limit setting. Keep in mind however that flexibility will be required.
- Tic symptoms tend to worsen toward the end of the day. Increased energy and effort spent controlling symptoms make concentration difficult. Therefore, plan academics accordingly.
- Because TS symptoms often wax and wane (sometimes daily), structure and planning must be flexible. Flexibility in the IEP may be appropriate. This presents a special challenge for the teacher.
- If a student requires a small student-teacher ratio, but yet does not qualify for services as learning disabled, a resource room setting may be appropriate under the category of Other Health Impaired (OHI/P.L.101-476, IDEA).
- Parents and teachers should communicate and work closely to allow for adequate social and emotional growth.

Visual Motor Impairment

- Visual-motor response speed slows down with copying tasks. This is due to: 1) the complex problem of shifting from a visual-receptive to a motor-expressive mode when copying from the chalkboard/overhead projector, or 2) a difficulty in sustaining attention with the repetitive nature of copy work (often seen when associated ADHD is present). Often this "slowness" is perceived as a problem of motivation rather than a neurological one.

- Photocopy materials rather than requiring the student to do copy work. Copying is time consuming and extremely frustrating for many students with TS.
- Pencil use may be slow and laborious due to involuntary pressing too hard, work-overs, repetitive erasing, and/or rituals such as counting words at the end of each sentence.
- Restrict or limit motor involvement. With problems involving pencil and paper tasks, provide alternatives such as dictation, typing, interactive computer programs, word processing programs, pre-writing programs and oral responses.
- Suggest the use of a 3"x5" card for visual tracking during reading assignments.
- For math work, turn lined paper sideways, allowing for column alignment for long division and two or three digit multiplication.
- If the student has a firm grasp of the problem-solving process being taught in math, consider the use of calculators to circumvent visual-motor difficulties in math.
- Allow extra time for written work or reduce the length (and therefore the time) required for completion of the assignment.
- In secondary school, tape lectures and allow for extended time and/or oral responses to tests.
- If word processing equipment is not available, allow the use of NCR paper. While the student with TS is otherwise engaged in notetaking, writing down key words or logging answers to study questions from a textbook, a peer helper can provide a copy of notes to that student.

Attention Deficit Hyperactivity Disorder (ADHD) and Poor Impulse Control

Involuntary, repetitive thought patterns may cause the child to "dwell" unnecessarily on a math problem, or in reading tasks he may "get stuck" on a particular sentence. This problem may be exhibited as excessive proof reading, rereading a paragraph or rechecking work. This is because thought processes

don't progress sequentially, but rather get "caught in a loop." Analogous to involuntary tics, this processing problem can be thought of as a "mental tic".

Because social maturation may be delayed, provide social experiences and opportunities to function with peers. Structure group work by giving specific tasks to members or by appointing partners or teams. Strive for cooperative not competitive tasks.

Typically, the student is aware of being poor at planning ahead. Simply put, this student's attempts to plan are disorganized. It is strongly recommended that the student be taught basic study skills (such as SQ3R) and organizational strategies such as: strategies for how to remember material; how to sequence tasks and break them down into manageable steps; and how to prioritize tasks for time management.

When teaching concepts, employ the concrete, experiential, and hands-on, rather than the abstract or strictly lecture approaches.

When teaching reading, pay special attention to blends, diphthongs as units, in conjunction with single letter phonetic approach. The Glass Analysis utilizing clusters in words is strongly recommended.

To improve attention while engaged in academic tasks, the student may benefit from simultaneously being involved in some type of motor or active response behavior – for example non-disruptive foot tapping (no shoes) or body rocking seem to meet sensory needs associated with TS.

Seating: Physical proximity to teacher for maintaining student's eye contact and attention. If motor tics are severe enough to cause the student embarrassment, then seating in front of room may not be advisable.

Structure assignments: Describe in writing what is expected – i.e. short lessons with assured completion. Finishing the task allows for a feeling of closure, improves self-esteem and serves as a motivator for the next text. For longer assignments requiring sustained attention, provide frequent breaks, and introduce novelty into the lesson. The use of movement, motion, or

any strong stimulus will capture attention and increase academic performance.

Difficulty with sustained attention interferes with development of rote skills. However, short term memory is not necessarily impaired. Remember academic performance and behavior are likely to worsen when sustained attention is required for a repetitive task or rote activity responses. This may be overcome with high levels of reinforcement.

Listening Tasks and ADHD

— Too much detail or descriptive information are likely to disrupt the student's listening comprehension. If information is presented in a complex format the student will have trouble with selecting out relevant material. This is especially true with younger children.

— Competing, non-relevant stimulation, e.g. interesting background classroom conversation (rather than non-specific background noise) will disrupt the student's ability to listen to the teacher.

— Provide global cues ("it looks like" or "it's similar to") rather than adding detail ("it has the following features").

Speaking Tasks and ADHD

– The student may be more talkative when they initiate conversation but less talkative when they're asked to respond.

— When answering a question, usually the student will not elaborate without external cues, e.g. pictures or prompts from the teacher.

— The addition of visual cues, novelty, or combined (auditory, visual, tactual) instructions can "normalize" the student's ability to correctly follow directions.

— In long term memory tasks, the student's performance will improve with cued recall (teacher prompts) vs. free recall.

— Remember, this student is less likely to ask for help – especially once he's already begun a task. Implications for the teacher are to monitor student at the beginning of an assignment rather than after it is well underway.

Written Math Skills and ADHD

The student's reading and cognitive abilities (including memory) are the most important skills needed for solving word problems. Each additional step – changes in action, operations, and order of operations, all add difficulty to problem-solving. This compounds problems of selective attention already inherent in this student.

Behavior Management and ADHD

— Response-Cost System (showing students that their actions result in consequences) is more effective in developing compliant behavior than positive reinforcement alone.

— When mild correction and short reprimands don't achieve desired results, stronger reprimands introduced suddenly are more effective in suppressing behavior than several repeated warnings – which typically end up in a power struggle with no winner.

— If medication is prescribed, observations of behavior and academic performance must be communicated to parents and shared with the physician.

— Cognitive Behavior Therapy is promising, but most studies have not yielded consistently positive results.

Obsessive Compulsive Symptoms and Ritualistic Behaviors

Since anxiety-provoking situations increase obsessions and compulsions, strive for a relaxed environment.

— Simply telling the student to get back to work often is not powerful enough to break the cycle of these behaviors. A teacher might start with "pick up your pencil, (pause for compliance), find number one in the text, (pause for compliance) copy that problem on your paper right here (touch paper)."

— Break the cycle of repetitive thought by initiating a "neutralizing process" e.g. change the environment, assign a physical activity or physically redirect.

— Ritual monitoring: Student and teacher together can develop a plan for a gradual reduction in the

time or number of rituals the student performs. This requires record keeping and charting.

— Redirect: the following suggestions may be less obtrusive but possibly not as effective as a physical prompt from the teacher.

Use of timer
Use of name
Proximity, eye contact

Cognitive Impairment

With learning and memory the best results are obtained with general concepts (global cues), or an initial overview before the presentation of specific facts. If fact learning is required, use demonstration, provide experience, incorporate audio-visual approach, or ask the child to perform in order to help process information. An overview that precedes specifics reduces impulsivity because a framework has been provided. Present the whole scope of new concepts so that the child will know where he is to go with information – in other words, where to plug it into his experience.

— Use interactive drill and practice computer programs for rote memory drill. Tutorial programs are helpful for initial instruction.

— The student's learning style may be holistic and deductive rather than sequential and inductive.

— Role-playing and video rehearsal with feedback will facilitate learning. Wherever possible, make tasks concrete by providing manipulative objects, models, pictures and diagrams.

Emotional Overlay

Since the teacher is the major "tone-setter" and support person in the classroom, ask the student what his feelings are about disclosure of TS to other teachers/students. Would he rather not have the class know? Would he prefer that someone else, or he himself share information about the disorder? Some do, some do not. Support means accepting a child's feelings about the issue. Remember the incredible power and responsibility of the teacher as

an acceptance model. A child in constant fear of betrayal by his body will have difficulty building a positive self-image. He will rely heavily on positive feedback from significant others throughout his school years.

— Work specifically to enhance self-image. This point is extremely important. The student may act as an aid or tutor to other students or perform special chores. A feeling of self-worth will help to overcome many obstacles.

— Teach use of relaxation techniques, visual imagery and auto-suggestion to enhance self-image and help develop a sense of control.

Testing Considerations

— Try to eliminate stress-provoking situations, e.g. timed tests in a quiet room. Allow for testing alternatives for the student. A separate area for testing allows the student to "release" tics without fear of disturbing others. He can direct his attention to test content and provide a truer evaluation of his subject knowledge.

— Allow for alternatives to traditional testing such as giving weight to daily assignments as an alternative to, or modification of testing.

— SAT and ACT testing environments can be negotiated with respective companies without violation of standard procedures.

— Machine-scored answer sheets (bubble type) are extremely difficult for people with visual-motor problems. Try to provide alternatives.

Glossary

Assistive Technology Devices and Services: Assistive technology *devices* are any items, equipment or products used to help a child function in the educational setting. Assistive technology *services* help a student select, obtain or use the device. These services can include evaluating the student's needs, providing the devices and services to match student needs, and training for the student, family, and school personnel in using the device. These services and devices must be made available to any student who needs them to benefit from instruction. They can be provided as special education, related services or as supplementary aids and services to the regular education program.

Code of Federal Regulations (CFR): The Code of Federal Regulations (CFR) contains the rules of the federal government. All agencies and facilities receiving funds under a federal law covered in this document must follow these rules. This includes all local school districts.

Consent: Your written permission is required *before* the school tests your child for special education for the first time and places your child in special education for the first time. In most instances, before the school can release confidential information from your child's education records, your written consent is also needed. The actions for which your permission is being requested must be fully explained by the school. Consent is voluntary and may be withdrawn in writing at any time. However, if you revoke consent after your child is first placed in special education, your child's current placement will not change unless: (a) you and the school agree otherwise or (b) a due process hearing resolves the dispute.

Due Process Hearing: A due process hearing is a formal legal procedure used to resolve disagreements concerning the education of students in special education. An impartial hearing officer conducts the hearing and makes decisions about the issues.

Extended School Year or Extended Year Services: These services are individualized instructional programs for eligible students in special education. They are offered over and above the traditional 180-day school year.

Free Appropriate Public Education (FAPE): Federal law mandates that students have the right to a free appropriate public education which includes special education and re-

lated services. This covers physical education services, (34 CFR 300.307). The public school provides these services at the preschool, elementary and secondary levels at no cost to parents. The programs and services must conform to the goals and objectives stated in the student's individual educational plan (IEP).

IDEA: Individuals with Disabilities Education Act (P.L. 101-476) 1990

Inclusion or Full Inclusion: The philosophy of education that promotes the concept that all students with disabilities should be educated in regular classrooms in their neighborhood schools.

Individual Educational Plan (IEP): The individual educational plan is developed with you (and where appropriate your child) as a member of the IEP committee. The IEP includes educational goals and objectives for your child. It documents the services your child needs, how services will be provided and how progress will be measured. To insure a FAPE, the IEP must be reviewed annually or as often as necessary.

LEA: Local Educational Agency

Least Restrictive Environment (LRE): To the maximum extent appropriate, your child has the right to an education in a setting with children who are not in special education. This setting is known as the least restrictive environment.

Mainstreaming: The process of integrating children with disabilities into regular education classrooms. This process is closely associated with the concept of Least Restrictive Environment (LRE). The term "mainstreaming" does not appear in IDEA.

Mediation (not available in all states): You may not always agree with the placement or educational program developed by the committee. Sometimes disagreements can be resolved through an impartial third party – a mediator. During mediation, you voluntarily meet with a school representative and the mediator to review your child's educational plan and work out solutions that are satisfactory to both you and the school. There is a difference between mediation and an impartial hearing. At mediation, the mediator facilitates communication between the school district and the child's parent or guardian to help them reach an agreement. At an impartial hearing, the hearing officer renders a decision based on evidence and testimony.

Notice: The school must inform you in writing about actions or proposed actions concerning your child's program. Whenever possible, notices will be written in your native language. If this is not possible, the school must use other means to ensure that you understand the information contained in the notice.

Regular Education Initiative (REI): A philosophy of education that promotes the concept that general education rather than special education should be responsible for the education of students with disabilities.

SEA: State Educational Agency

Special Education: Special education means instruction and related services provided by special education personnel. These can be provided by a regular education program modified through special education support services, supplementary aids or other special arrangements.

Transition Services: The purpose of transition services is to identify the skills and services a student will need to move smoothly from school to adult settings. If your child is at least 16 years old (or younger if needed), you will be invited to help develop an individual transition plan. This is a long-range planning document that addresses the following areas: employment, education, independent living, recreation/social/leisure activities and general considerations such as transportation, income/resources and medical services. The document is reviewed every year, and should include interagency involvement as needed.

Professionals and their Roles

Child Psychiatrist: Concerned with the emotional problems of children and youth. Trained as an observer and interpreter of human behavior. Helps an individual develop more positive feelings about self, family, and the environment in which the individual lives. Recommendations for a treatment plan might involve the use of medication to alleviate stress, individual counseling or psychotherapy, or a combination of both. Holds either a Doctor of Medicine (M.D.) with certification in both general psychiatry and child psychiatry from the American Board of Psychiatry and Neurology or a Doctor of Osteopathy degree (D.O.) with certification by the American Osteopathic Board of Psychiatry and Neurology.

Clinical Psychologist: Skilled in diagnosing and treating emotional problems. The psychologist is trained in the behavioral sciences (not medicine) and is skilled in individual and group counseling and psychotherapy. A sub-specialty in clinical psychology that deals specifically with the emotional, social, and intellectual development of children is called child-clinical. Educated in the field of psychology and holds either a Master's degree (e.g., M.A., M.S.) or Doctoral degree (e.g., Ph.D., Psy.D.) in the specialty of clinical psychology.

Neurologist: Specializes in diagnosing and treating disorders of the central nervous system and tries to find out if the central nervous system is working properly and what is causing any problems. Holds a Doctor of Medicine (M.D.) or Doctor of Osteopathy degree (D.O.). Pediatric neurologists work primarily with infants and children.

Occupational Therapist: Trained to help the individual develop skills through therapy and adaptation of the tools of everyday life to compensate for physical disabilities. Holds at least a Bachelor's degree (e.g., B.A., B.S.) in the specialty of occupational therapy. Training entails study in child development, motor and perceptual skill development and the therapeutic rehabilitation of daily living skills. The Registered Occupational Therapist (O.T.R.) has completed the national certification examination of the American Occupational Therapy Association.

Ophthalmologist: A physician who specializes in diseases of the eye and eye injuries. Also able to assess why an individual is having a problem seeing clearly and to prescribe corrective lenses. Degrees held by an ophthalmologist are either a Doctor of Medicine (M.D.) with a certification by the

American Board of Ophthalmology or a Doctor of Osteopathy (D.O.) with certification by the American Osteopathic Board of Ophthalmology.

Pediatrician: A medical doctor specializing in the care and treatment of children and youth. Holds either a Doctor of Medicine degree (M.D.) certified by the American Board of Pediatrics or a Doctor of Osteopathy degree (D.O.) with certification by the American Osteopathic Board of Pediatrics.

Physical Therapist: Specializes in developing the strength and endurance of the body parts, developing normal motor patterns, and in helping individuals with disabilities become as physically independent as possible. Has trained in the therapeutic use of movement and physical activity, holds at least a Bachelor's degree (e.g., B.A., B.S.) with a specialty in physical therapy. Has completed the appropriate licensing board examinations.

School Psychologist: Concerned with the way a child learns and adjusts to the school situation; assists in the identification of learning and behavioral problems. Holds either a Master's degree (e.g., M.A., M.S.) or Doctoral degree (e.g., Ph.D., Psy.D.) in school psychology, and has completed the appropriate licensing board examinations.

Social Worker: Carries out a wide range of tasks in a variety of settings. Is concerned with ways the children and their families cope with special difficulties and may provide counseling services to help them overcome problems. Knowledgeable about community resources and typically works closely with other professionals who are dealing with either the child or the family. Usually holds a Master's degree (M.S.W.) in the specialty of social work.

Special Education Teacher: Responsible for providing direct help in school-related problems. May work in a variety of education environments ranging from public school resource room or self-contained programs to more restrictive settings such as hospitals and residential institutions. Holds at least a Bachelor's degree (e.g., B.A., B.S.) and has the appropriate teaching endorsement from the educational agency.

Speech Pathologist (Clinician): Evaluates a child's speech and language development, identifies problems, and recommends and implements interventions. Holds at least a Master's degree (e.g., M.A., M.S.) in the specialty of speech pathology.

PLACES TO CONTACT

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, NY 11361-2857
(718) 224-2999
(800) 237-0717

Office for Civil Rights (OCR)
Department of Education
330 C Street S.W., Room 5000
Washington, DC 20202
(202) 205-8635
(800) 431-3481

Office of Special Education Programs
330 C Street S.W., Room 3086
Washington, DC 20202
(202) 205-5507

National Association of Protection
and Advocacy Systems (NAPAS)
900 Second Street, N.E., Suite 211
Washington, DC 20002
(202) 408-9514

TSA is grateful to Ecological Fibers, Inc. and M & M Bindery for their generous contributions to this publication.

ADDITIONAL RESOURCES

VHS FILMS

An Inservice Film For Educators: A Regular Kid, That's Me — A new aid for teachers to help understand the complexities of teaching children with TS. Includes explanation of the complexities of TS and suggests interventions that work.

Stop It! I Can't — For elementary school ages. Written to create sensitivity and reduce ridicule among their peers.

I'm A Person Too — Prize winning documentary featuring five people from diverse backgrounds talking about living with TS; depicts the broad range of symptoms.

Tourette Syndrome: The Parent's Perspective — Diplomacy in Action — Features E. Collins, Ph.D. and R. Fisher, M.Ed., providing guidance to TS families on school advocacy issues.

LITERATURE

Coping with TS — A Parent's Viewpoint — E. Shimberg. Covers parental and family acceptance, behavior management. (Revised 1993)

TS & the School Nurse — S. Ort, R.N. Comprehensive guide to educational, social and medical implications.

Problem Behaviors & TS — Drs. R. Bruun, and K. Rickler. Describes recent research and what is now known about the relationship of a variety of behaviors and TS. Contains helpful advice by Emily Kelman-Bravo, CSW, MS about the management of problem behaviors for families and individuals with TS. (Revised 1993)

Discipline and the Child with TS: A Guide for Parents and Teachers — R. Fisher-Collins, M.Ed., 1993. Helps children redirect impulses and compulsions through teaching cause and effect relationships. Included are techniques and disciplining children without the use of aggression or intimidation.

An Educator's Guide to Tourette Syndrome — S. Bronheim, Ph.D. Covers symptoms, techniques for classroom management, attentional, writing and language problems.

An up to date Catalog of Publications and Films, including prices, can be obtained by writing to:

TOURETTE SYNDROME ASSOCIATION, INC.
42-40 Bell Boulevard
Bayside, NY 11361
Tel # (718) 224-2999
Fax # (718) 279-9596

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8M/1994